

Minutes of January 13, 2006
Quality of Life Subcommittee
Comprehensive Cancer Control Plan

Chair: Dr. Don Brooks
Co-Chair: Patricia Harmon

In attendance: Christina Emmerich, Rosemarie Dominguez , Brenda Keith, Marcey DiCaro, Tani Bahti, Stan Weintraub, Stephen Coons, Margaret Hoeft, Susan Leigh, Paula Hardison, Pat Prinski, Don Brooks, Patricia Harmon

ACTIONS:

Don, Paula and Patricia to work on formats for talking points for patients to use in discussing long term survivorship issues with their physicians. They will also research what forms are being developed to help patients with their individual treatment synopsis and post-treatment counseling by their oncologists. (This could also go on the website).

Carol Hardy and Paran to work on the Resource Directory. This is intended as a comprehensive resource directory that could be maintained at the ACCC website. The need to fund such a project was discussed. This effort should be coordinated with the diagnosis and treatment committee (which is performing a gap analysis). Rosemarie Dominguez offered to assist.

Subcommittees encouraged to meet between now and the next meeting.

MINUTES

Dr. Brooks distributed a handout outlining the set of objectives for the Quality of Life Committee, and introduced Susan Leigh, an oncology nurse, cancer survivor, and member of the National Cancer Coalition on Survivorship. Each QL meeting will feature an educational speaker to inform the committee on critical issues facing Quality of Life for cancer patients. Future speakers include Brenda Keith and Marcey DiCaro on Patient Navigation (April) and Stephen Coons in June (Definitions of QoL and research measures)

Key Points from Presentation by Susan Leigh

Survivorship is slowly beginning to take importance as an issue

Once treatment is completed, patients are booted out of the nest and yet many critical issues remain to be dealt with

There are no evidence-based programs to describe the optimal protocol for survivors

NCCS is beginning to find a voice

The perspective of survivorship is a process not 2, 5, or 10 years without a reoccurrence

A false sense of security exists because there is no guarantee of not having a reoccurrence and the effect or impact of treatment is unknown

Survivorship begins once a diagnosis is made

There are three seasons of survival: diagnosis, treatment and remission

NCCS deals with numerous issues including palliative care, end of life, access to adequate care at end of life, access to quality care during cancer care

Conflicting ways of looking at cancer survivorship; the medical community wants to see survivorship defined by the stage of survivorship; survivors want to define it as a process.

The question to be asked is what happens once they go off therapy

There is a need for consensus based guidelines for survivors while evidence based research is being developed
Important to address psychosocial issues and financial issues
Many existential issues related to cancer

Suzie showed a book, "From Cancer Patient to Cancer Survivor." Parts of this text can be downloaded at the Institute of Medicine and the National Academy of Science.
The websites are: www.IOM.org and www.nationalacademies.org

A discussion ensued:

The group agreed we need to help patients learn to deal with issues related to survivorship.

The medical model is that medical doctors would work with a healthcare team to develop an exit meeting accompanied with a plan. It would be a cancer care plan including short-term goals, how often you should see your physician, long-term goals. It would also include your pathology reports, medication dosages, etc. It would also help you identify your psychosocial issues.

Access to care and preexisting issues are a problem.

Follow-up care is horrible and employee-based insurance is a significant problem in our nation.

The question was asked if we could advocate encouraging our physicians to conduct an exit interview. Nurses are a viable solution. How can we teach nurses to be more involved? There needs to be an integrative approach.

Susan noted that long-term follow up models do exist; generally based on the pediatric oncology models. Lance Armstrong Foundation is funding 3 locations for start up survivorship clinics.

Tani mentioned The University of Wisconsin has a Department of Partnership, Center for Patient Partnership

Lance Armstrong Foundation has a Survivorship Notebook that is free and you can receive by writing.

REPORTS

Pat Priniski reported on her work on Action item 4.4 Palliative care. She is seeking to put together a subcommittee. With more representatives of hospice present, leadership and specific actions of the committee should be defined soon: one direction this group would like to take is to develop a specific questionnaire and perform a belief and referral pattern study among referring physicians and providers.

Paula Hardison reported that Shirley Agnos, executive director, Arizona Town Hall is considering integrating the CCCP into a Spring 2007 statewide forum to discuss health access and disparities. This spring we will have contacted the disparities committee (and others) to develop a coordinated presentation that could be a portion of that town hall.

Paran Pardell has obtained and sent a disc of the breast cancer support directory developed by the Arizona Women's Cancer Network. It includes: care providers; palliative care groups, travel, and monetary issues.

GRANTS SOUGHT

Where resources could be found to support work of the Quality of Life committee was discussed, BHHS Legacy Foundation as well as the Grantmaker's Forum in Phoenix was suggested.

PATIENT NAVIGATORS

Brenda Keith had e-mailed an article from Cancer (the medical journal) on the use of navigators for underserved patients.

The benefits of patient navigators were discussed. They help with barriers, but not a lot of research is available to show their effectiveness. Center for Mind Body Medicine has done a little bit of research of navigators. Brenda Keith, Marcey DiCaro will continue to research this and plan to have a presentation on various navigation models in use and on any available outcomes research.

NEXT MEETINGS: April 6 – Phoenix; June 28 – Phoenix; Sept. 14 – Tucson

Respectfully Submitted by: Paula Hardison, January 23, 2006